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AN EVALUATION OF PARENTAL SATISFACTION
WITH EARLY INTERVENTION SERVICES
THROUGH INLAND REGIONAL CENTER


A Project
Presented to the
Faculty of
California State University,
San Bernardino

by


Ann-Marie Wazdatskey


June 1993

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In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

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ABSTRACT

This report is about a study that evaluated the satisfaction level of parents receiving services through either the Follow Up Intervention for Normal Development (F.I.N.D.) program or the Infant Program at Inland Regional Center. Both programs served families with infants who are considered to be "at-risk" of having a developmental delay; however, the programs operated in a significantly different manner. This study evaluated how parents feel about the services they are receiving from Inland Regional Center, an agency which serves the developmentally disabled. Their responses have provided valuable information for social workers and others who provide services to this special "at-risk" population. This study adopted a positivist approach and the data is descriptive in nature.

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INTRODUCTION

There is a special population of infants who are considered to be "at risk" for having a developmental delay. This "at risk" population includes the following: low birth weight pre-term infants (under 3 pounds); infants that have experienced difficulties during birth and delivery, or severe illnesses, such as meningitis and encephalitis; infants with feeding problems leading to slow weight gain; special situations such as severe head injury, seizure activity, prolonged hospitalization, birth defects; infants dependent on life sustaining technology; and infants with identifiable syndromes.

Inland Regional Center has two programs serving the families of "at risk" infants: Follow Up Intervention for Normal Development (F.I.N.D.) and the Infant Program. Both programs support these families by providing ongoing case management services which provide information and referral to community and other specialized services. Social support is also provided to assist families in coping with issues of caring for an infant with medical or developmental problems.

The programs differ in their operating procedures. F.I.N.D. case managers receive their referrals directly from the hospital neonatal intensive care units. They complete their own intakes with client families and initial contact with families is made while the infant is

still in the hospital or shortly after discharge. The F.I.N.D. case managers provide routine assessments to monitor the infants' level of development by using the Denver Developmental Screening Test and the Bayley Scale of Infant Development. They also provide physical examinations including height-weight grids, and tests for expressive and receptive language development.

Clients in the Infant Program may or may not have been identified at birth as being "at risk" of having a developmental delay. These families are usually referred to Inland Regional Center by hospital social workers, discharge planners or pediatricians. Parents must call Inland Regional Center and make an appointment to be seen by the Intake and Assessment Unit. It may be four to five months before ongoing case management can begin. Their caseloads tend to be larger than F.I.N.D. caseloads and the infants they follow tend to have more chronic impairments. The majority of these infants usually have a diagnosis of mental retardation, cerebral palsy, epilepsy or autism by the age of three. Thus, they have a developmental disability and are eligible for long-term Regional Center services.

Many of the infants in the F.I.N.D. Program do not have these diagnoses by age three and their cases are closed. If they do, the child is then transferred to an Infant caseload for ongoing case management. F.I.N.D.

only follows infants until age three at which time the cases are either closed or transferred to the Infant Program. The Infant Program follow infants from zero to five years of age.

Problem Statement

The purpose of this study was to compare and evaluate the satisfaction level of parents who were receiving ongoing case management services through either the F.I.N.D. or Infant programs. The data has been used to determine whether one program was perceived as more effective than the other in meeting the needs of parent with "at-risk" infants.

Problem Focus

Parental satisfaction is important because the goal of both of these programs is successful integration of the "at-risk" infant into the family. This can be achieved by providing ongoing case management, information and referral, supportive counseling and education. The parent satisfaction survey adopted a positivist approach and evaluated the direct practice social work role. Parents in both programs were asked to complete the survey and their responses were compared and evaluated to determine if there was a difference in parent satisfaction. This survey also identified what services parents regarded as helpful or not helpful.

Literature Review

Research has been done on the importance of early intervention for infants "at risk" and the need for support for parents who are dealing with infants who have multiple health problems. Some research has looked at the relationship between social support and parental adjustment to low birth weight infants.

Phillipp (1984) found that parents' ability to use social support was highly related to their adjustment to their infant following discharge from the hospital.

McCubbin (1980) addresses the relationship between the daily stresses and demands of caring for a chronically disabled child and the need for not only a flexible nuclear family relationship but also the need for formal social services support. According to Fenichel (1991) consensus has been developing around principles that lead to quality infant/family programs. These principles are reflected in accreditation standards for service programs and professionals. Such standards state that services for infants and toddlers and their families must be specially assigned and cannot be scaled down versions of programs for older children, and that infants and toddlers must be understood and served in the context of their families.

Research completed by Mercer and Chavez (1989) evaluated the level of parental satisfaction with services being provided by Regional Centers in California. They

found that Infant Stimulation and early intervention programs for infants zero to three were highly regarded by parents. These authors further state that parents' comments about their experience with early intervention programs were uniformly positive.

The F.I.N.D. Program specializes in infant development and the major focus is on teaching parents about how to care for their "at risk" infant. The Infant Program does not specialize in just infants. The case managers serve a larger population with chronic health problems, and severe physical and developmental impairments.

The rationale for looking at parent satisfaction between the two programs was to evaluate if all "at risk" infants and their families should be receiving specialized services, such as those in the F.I.N.D. Program.

RESEARCH DESIGN AND METHODS

The purpose of this study is to assess parental satisfaction with the services provided by the F.I.N.D. Program and the Infant Program at Inland Regional Center. This is an exploratory study to find out if there is a difference in the level of parental satisfaction between the parents being served in the two programs. Parental satisfaction was measured in two ways: a Likert scale of inquiries regarding certain features of the program, and open-ended questions.

Qualitative data was collected via the open-ended questions about services parents regarded as helpful or not helpful. Respondents were also given an opportunity to give constructive feedback about the program in which they were being served.

Research Question and Hypothesis

The research question addressed by this study was: What is the level of satisfaction of parents being served by the F.I.N.D. and Infant programs? The hypothesis was that there would be a difference in the level of satisfaction between the parents being served by the F.I.N.D. Program and parents being served by the Infant Program.

Sampling

The population of interest in this study is the parents of infants zero to three years of age who had active cases at Inland Regional Center. These parents were receiving case management services from either the F.I.N.D. or Infant Programs. All infants had the diagnosis of being "at-risk" of having a developmental delay.

The F.I.N.D. unit had a total of 710 clients and the Infant unit had a total of 350 clients who were under the age of three and diagnosed "at-risk" of having a developmental disability.

One hundred families were selected from each group.

The samples were selected using systematic random sampling using the Table of Random Numbers.

The data was collected by the attached survey (Appendix A). The instrument collected demographic information about the caregiver of the clients in the two programs, along with the responses on the survey questionnaire about their satisfaction with the services they were receiving. The survey also included two open-ended questions about services that were regarded as helpful or not helpful.

The questionnaires were distributed over a three month period, from September 1992 through November 1992. Approximately twenty-four case managers actively participated in the distribution of the survey. The questionnaires were usually given to caregivers at time of the client's quarterly review. They were asked to complete the survey and return it in the self-addressed stamped envelope. This was done to lessen the pressure on the caregiver to complete the survey while the case manager was present.

Informed Consent

Each participant was asked to sign a consent form and return it with their survey. The consent form (Appendix B) stated that their responses would be kept anonymous and also guaranteed that services they were receiving from Inland Regional Center would not be affected by their

participation in the study. The surveys were returned to this M.S.W. student in the self-addressed stamped envelopes. The signed consent form was immediately separated from the review.

DATA ANALYSIS

Data were analyzed using "EPI INFO Version 5", A Word Processing Data Base, and Statistics System for Epidemiology on Micro Computers. Frequencies for both groups were obtained and compared. The Chi Square statistical test was used to test the significance of each response. The responses were then combined to show a composite of the sample populations. (See Appendix C).

The quantitative data were tallied by program for comparison and then combined for total responses. The qualitative data were separated by program and were content analyzed.

RESULTS

Forty percent of both sample populations surveyed responded to the questionnaire, for a total of 83 respondents. The respondents were primarily white females in the age range of 17-57 with a mean age of 31. Seventy-two percent of the respondents were white, nine percent were African-American, fifteen percent were Hispanic, and two percent were Asian. Eighty-two percent of the respondents were married, while five percent were either separated or divorced and thirteen percent were

single. The average annual income of the respondents was between \$21,000 and \$40,000, while fifteen percent of the respondents had annual income of under \$10,000 and fourteen percent indicate that they had annual incomes over \$51,000. Seventy-two percent of the respondents had two or more children, while twenty-eight percent had only one child.

Out of the total of eighty-three respondents to the survey, seventy-seven of the surveys were completed by the parent as the caregiver of the child, while only six were completed by grandparents or foster parents as the caregiver of the child. The typical respondent was a white female, married, with 2 or more children and an average annual income between \$21,000 and \$40,000.

Satisfaction

Parents were asked to respond to evaluative questions on a rating scale of strongly agree to strongly disagree. There were a total of seventy questions that covered areas such as intake process, explanation of regional center services, case manager's interest and support, case manager's knowledge of infant development, the Individual Program Plan (IPP) process, community referrals and school issues. The majority of all respondents from both programs indicated they agreed or strongly agreed about their satisfaction with the services they were receiving.

In many cases there was no difference in the level of

satisfaction between the two groups. Both reported an overall high level of satisfaction. (Questionnaire results in Appendix C).

The qualitative data collected in the survey allowed participants to indicate what services were considered the most helpful. Of the eighty-three respondents a total of sixty-two indicated that visits with their case manager were the most helpful. Forty indicated that referrals to community services were most helpful and twenty-five participants indicated that the purchase of services were considered the most helpful. Only three respondents indicated quarterly visits were not helpful, four respondents felt referrals to community services were not helpful and five indicated that purchase of services were not helpful. Five respondents indicated that attendance at the IEP was not helpful.

The individual comments from all the questionnaires were divided into three categories; twenty-six were worker related, nine were service related and eight were referral related. There were a total of forty-three individual comments.

The worker-related responses were mainly focused on caregivers' feelings about their specific case manager. Their comments generally related to the case manager's helpfulness, caring attitude and assistance in securing services for their child.

The service-related responses were directed at the purchase of service by Inland Regional Center. The services mentioned included the purchase of special formulas, respite care, and infant stimulation programming.

Responses about referrals were generally related to the helpfulness of specific referrals that were made by the case manager to assist the client and family, such as referrals to California Children Services, school programs, Social Security, and the Elks Major Project for physical therapy or occupational therapy, to mention a few.

There were eight negative comments but they were not specific in content. They tended to be more of a statement of general dissatisfaction with services respondent may or may not have received.

Typical comments from parents served in the F.I.N.D. Program include: "My case manager is excellent!", "We appreciated everything that has been done for our family.", "My case manager is very caring and knowledgeable.", and "Excellent program!".

Typical comments from parents served by the Infant Program include: "I appreciate the ongoing support.", "All services have been helpful to us.", and "Our family is grateful for the guidance and support we have received for ur daughter's continued growth."

Trends

There was a significant trend in the data that should be noted in seven of the seventeen items. It appears that the caregivers from the F.I.N.D. Program responded with more strongly agreed responses to the questionnaire than the caregivers from the Infant Program. This was particularly evident in questions that related specifically to case manager's knowledge of infant development, support and parents as active participants in infant's Individualized Program Plan (IPP).

Table 1 illustrates the more positive satisfaction scores of the F.I.N.D. caregivers in given areas. Specifically items 4, 10, 11, 13, 15, 16, and 17. These items did test to be statistically significant.

Table 1

Comparison of Satisfaction of Parents of Project FIND
and the Infant Program (n = 86)

	<u>FIND</u>		<u>Infant</u>		X ²
	Strongly Agree	Agree	Strongly Agree	Agree	
I am satisfied with:					
1. Intro to RC	27	12	24	16	.67NS
2. RC Services/Intake	28	11	22	16	1.75NS
3. CM explain RC	29	10	24	13	1.02NS
4. Timely CM Service	28	11	21	17	6.15*
5. Ongoing CM explain	26	12	20	18	2.57NS
6. CM knowledge community	25	14	17	21	3.88NS
7. CM knowledge schools	22	12	14	21	3.17NS
8. CM availability	26	14	15	18	5.26NS
9. CM phone calls	31	10	20	18	5.64NS
10. CM interest infant	35	5	21	14	7.88*
11. CM knowledge infant	36	5	19	19	12.69***
12. Program help	34	7	26	12	5.36NS
13. Parent active IPP	30	7	22	18	6.33*
14. IPP address needs	20	13	14	20	2.38NS
15. CM support	35	4	23	15	8.82*
16. CM info stimulate infant	34	6	16	17	16.21***
17. CM knowledge infant needs	33	8	15	18	11.01**
* = .05					
** = .01					
*** = .001					

The total results did support the hypothesis that there would be a difference in the level of parental satisfaction between the two programs. However, survey participants from both programs had very similar responses and they were overwhelmingly positive.

DISCUSSION

It appears that the response to this study supports current research on the need for early intervention and social support for families with "at-risk" infants. The findings clearly demonstrate that caregivers are satisfied with the services they are receiving.

Possible reasons why caregivers from the F.I.N.D. Program had significantly higher strongly agree responses in seven of the seventeen evaluative questions could be that the entire focus of the F.I.N.D. Program is on enhancing infant development. The F.I.N.D. caseloads tend to be smaller and less diversified than the caseloads in the Infant Program. F.I.N.D. case managers emphasize regular testing and evaluation of infants' progress and promote parental involvement and education. Another factor may be that the babies in the Infant Program often have more chronic and severe physical and mental impairments and may not demonstrate appreciable gains in their overall development as quickly as babies followed in the F.I.N.D. Program. The results of these seven questions were statistically significant demonstrating

that the F.I.N.D. case managers are probably more focused on infant development and parent education.

Limitations

There are, however, some limitations of this study that must be addressed. First, the survey was in English only and was not culturally sensitive to those families who do not read or write in English. A true representative sample of families served by either of the two programs was not able to be collected. Sixteen percent of families served by the F.I.N.D. and Infant Programs are monolingual and were not included in this study.

Another limitation of this study is the reliability of satisfaction surveys. According to Grinnell (1981) a disadvantage with survey questionnaires is that there is a good possibility of having a biased sample, since motivated and curious people might respond and others might not. Grinnell (1981) further states that it may be difficult to generalize findings if there is a high non-response rate. Roughly, only forty percent from each group responded to this survey which makes it a relatively small sample population.

Implications for Research and Practice

This survey was limited to parents with children under three, who have only been involved with Regional Center for a limited amount of time. Further research

could be done on parental satisfaction of parents with older children who have been receiving Regional Center services for a longer period.

An implication for social workers working with parents of this special "at-risk" population is to remember that these parents are very vulnerable and unsure of what the future holds for their children and themselves. They must have consistent support and encouragement, along with education to help them provide optimal care for their infants. This is evident by the sixty-two responses that were made by parents or caregivers about the helpfulness of regular quarterly contacts with case managers.

The hypothesis was proven in the areas of caregivers satisfaction with: the timeliness of case management services; case managers' support, interest and knowledge of infant development; case managers' provision of information on how to stimulate and exercise infant; case managers' knowledge of infant's special needs; and caregivers' involvement in Individual Program Plan (IPP) process. Responses demonstrate that service to this population should be continued with emphasis on infant growth and development, infant stimulation, parent education, and family involvement. Case managers should assist in developing a coordinated program with available community resources to provide a comprehensive Individual

Family Service Plan (I.S.F.P.) to meet not only the needs of the "at-risk" infant, but of the family as well.

Caring for an infant with health and physical problems can be an emotional as well as a physical challenge for families. Parents with "at-risk" infants under three appear to be overwhelmingly satisfied with the services they receive from Inland Regional Center, without regard to program. This supports the premise that early intervention and follow up with these families is greatly appreciated.

APPENDIX A

SURVEY

To be answered by person completing questionnaire. Circle your response or fill in the blank.

1. Male Female

2. Caregiver

Parent
Legal Guardian
Grandparent
Foster Parent
Other

3. Ethnicity: White Black Hispanic Native American Asian

Other _____

4. Age: _____

5. Marital Status

Married
Separated
Divorced
Single
Widowed

6. Income

Under \$10,000
10,000 - 20,000
21,000 - 30,000
31,000 - 40,000
41,000 - 50,000
51,000+

7. Number of Children: _____

	4 Strongly Agree	3 Agree	2 Disagree	1 Strongly Disagree
1. I am satisfied with the way I was referred to the Regional Center.				
	4 SA	3 A	2 D	4 SD
2. I am satisfied with Regional Center services and the intake process.				
	4 SA	3 A	2 D	4 SD
3. I am satisfied with my case manager's explanation of Regional Center services.				
	4 SA	3 A	2 D	1 SD
4. Case management services were started on a timely basis.				
	4 SA	3 A	2 D	1 SD
5. Ongoing case management services were explained to me at time of intake.				
	4 SA	3 A	2 D	1 SD
6. I am satisfied with my case manager's knowledge of community resources.				
	4 SA	3 A	2 D	1 SD
7. I am satisfied with my case manager's knowledge of school issues.				
	4 SA	3 A	2 D	1 SD
8. I am satisfied with the availability of my case manager.				
	4 SA	3 A	2 D	1 SD

9. My case manager returns my calls on a timely basis.

4	3	2	1
SA	A	D	SD

10. I am satisfied with my case manager's support and interest in my infant's development.

4	3	2	1
SA	A	D	SD

11. I am satisfied with my case manager's knowledge of infant development.

4	3	2	1
SA	A	D	SD

12. I feel this program has been helpful to my infant.

4	3	2	1
SA	A	D	SD

13. I am an active participant in the development of my infant's Individual Program Plan (IPP).

4	3	2	1
SA	A	D	SD

14. Our family needs are addressed in the Individual Program Plan (IPP).

4	3	2	1
SA	A	D	SD

15. My case manager responds in a supportive and helpful manner.

4	3	2	1
SA	A	D	SD

16. My case manager has provided helpful information on how to stimulate and exercise my infant.

4	3	2	1
SA	A	D	SD

17. My case manager is knowledgeable about my infant's special medical needs.

4	3	2	1
SA	A	D	SD

Services that are provided through Inland Regional Center that I regard as the most helpful.

1. Referrals to community agencies.
 2. Quarterly visits with my case manager.
 3. Purchase of services; i.e. respite care, special formula, behavior modification, infant programming.
 4. Attendance at IEP meeting.
 5. Other:
-
-

Services that are provided through Inland Regional Center that I regarded as not helpful.

1. Referral to community agencies.
 2. Quarterly visits with my case manager.
 3. Purchase of services; i.e. respite care, special formula, behavior modification, infant programming.
 4. Attendance at IEP meeting.
 5. Other:
-
-

Any other comments:

APPENDIX B

Informed Consent

I understand that my participation in this survey will in no way affect the services I am currently receiving from Inland Regional Center. I further understand that this consent form will be removed from my questionnaire before the survey is processed and will not jeopardize the anonymity of my responses.

Parent/Guardian

APPENDIX C

DEMOGRAPHIC INFORMATION OF SAMPLE POPULATIONS

	F.I.N.D.	INFANT	TOTALS
<u>Gender</u>			
Male	2	3	5
Female	39	38	77
<u>Caregiver</u>			
Parent	38	39	77
Legal Guardian			
Grandparent		1	1
Foster Parent	3	1	4
Other		1	1
<u>Ethnicity</u>			
White	32	28	60
Black	5	3	8
Hispanic	2	11	13
Native American			
Asian	2		2
Other			
<u>Age</u>			
15 - 20	2	2	2
20 - 30	16	15	31
30 - 40	16	21	37
40+	4	2	6
<u>Marital Status</u>			
Married	32	36	68
Separated		2	2
Divorced	1	1	2
Single	8	3	11
Widowed			
<u>Income</u>			
Under \$10,000	6	6	12
10,000 - 20,000	9	6	15
20,000 - 30,000	7	8	15
30,000 - 40,000	7	9	16
40,000 - 50,000	7	3	10
50,000+	3	8	11
<u>Number of Children</u>			
1	14	10	24
2	15	12	27
3 or more	12	20	32

SURVEY RESULTS

1. Satisfaction with introduction to Regional Center Services and intake process.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	24	16	1	1
FIND	27	12	1	1
Total	51	28	2	2

2. Satisfaction with Regional Center services and intake process.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	22	16		3
FIND	28	11	2	
Total	50	27	2	3

3. Satisfaction with case manager's explanation of Regional Center services.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	24	13	1	2
FIND	29	10	2	
Total	53	23	3	2

4. Case management services began on a timely basis.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	21	17	3	1
FIND	28	11		
Total	49	28	3	1

5. Ongoing case management was explained at time of intake.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	20	18	2	2
FIND	26	12	2	
Total	46	30	4	2

6. Satisfaction with case manager's knowledge of community resources.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	17	21	1	2
FIND	25	14	1	
Total	42	35	2	2

7. Satisfaction with case manager's knowledge of school issues.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	14	21	1	3
FIND	22	12	3	1
Total	36	33	4	4

8. Satisfaction with case manager's availability

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	15	18	3	1
FIND	26	14		
Total	41	32	3	1

9. Satisfaction with case manager's return phone calls.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	20	18	1	1
FIND	31	10		
Total	51	28	1	1

10. Satisfaction with case manager's support and interest in infant's development.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	21	14	1	1
FIND	35	5	1	
Total	56	19	2	1

11. Satisfaction with case manager's knowledge of infant development.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	19	19	1	1
FIND	36	5		
Total	55	24	1	1

12. Program's helpfulness to infant.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	26	12	1	2
FIND	34	7		
Total	60	19	1	2

13. Parent as active participant in IPP process.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	22	18	1	
FIND	30	7	2	
Total	52	25	3	

14. Family needs are addressed the IPP.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	14	18	1	1
FIND	20	13	4	
Total	34	31	5	1

15. Case manager responds in a supportive and helpful manner.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	23	15	1	1
FIND	35	4	2	
Total	58	19	3	1

16. Case manager provided helpful information on how to stimulate and exercise my infant.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	16	17	4	3
FIND	34	6	1	
Total	50	23	5	3

17. Case manager is knowledgeable about my infant's special needs.

	Strongly Agree	Agree	Disagree	Strongly Disagree
Infant	15	18	4	2
FIND	33	8		
Total	48	36	4	2

Services that are provided through Inland Regional Center that are regarded as the most helpful.

	F.I.N.D.	INFANT	TOTALS
1. Referrals to community agencies.	19	21	40
2. Quarterly visits with case manager.	36	26	62
3. Purchases of services; i.e., respite care, special formula, behavior modification, infant programming.	14	10	24
4. Attendance at IEP meeting.		7	7

Services that are provided through Inland Regional Center that are regarded as not helpful.

	F.I.N.D.	INFANT	TOTALS
1. Referral to community agencies.	2	2	4
2. Quarterly visits with case manager.	1	2	3
3. Purchase of services; i.e., respite care, special formula, behavior modification, infant programming.	3	2	5
4. Attendance at IEP meeting.	3	2	5

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